Vulnerability, Law, and Dementia: An Interdisciplinary Discussion of Legislation and Practice

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Legislation for dementia care needs to be continually rethought, if the rights of older persons and other persons with dementia are to be addressed properly. We propose a theoretical framework for understanding vulnerability and dependency, which enables us to problematize the currently prevailing legal conception of adults as always able — irrespective of health or age — to act autonomously in their everyday lives. Such an approach gives rise to difficult dilemmas when persons with dementia are forced to make decisions on their own about basic living conditions, such as housing and care, without decision-making support. In Sweden, for example, such matters are frequently left to the person him- or herself to decide, often without any assistance from social workers, and with family members serving as caregivers of last resort.

Using vulnerability theory as the framework for our discussion, we argue that policymakers should not apply a group-oriented approach (based on factors like age, legal status, or mental capacity) to persons suffering from dementia. The needs of such individuals are as complex and varied as they themselves are. We discuss our findings from an interdisciplinary (law/social work) research project in which we examine the dilemma that social workers face when they are required, under the terms of the Swedish Social Services Act, to determine whether persons with dementia are to be granted support.

We argue further that a cross-disciplinary approach — in which vulnerability theory furnishes the framework — opens up for new ways

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Cite as: Titti Mattsson & Lottie Giertz, *Vulnerability, Law, and Dementia: An Interdisciplinary Discussion of Legislation and Practice*, 21 THEORETICAL INQUIRIES L. 139 (2020).

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of understanding and developing social welfare law and practice. This, we believe, can help us better address the rights, interests, and needs of people with dementia, of their families, and of professionals in the social welfare system. Finally, many of the problems faced by ageing societies in general can be understood on the basis of such an approach.

INTRODUCTION

In this Article we will discuss some dilemma of law, social work and dementia. In chapter I the theoretical framework of the study will be introduced. Chapter II and III are devoted to the Swedish case, from the perspectives law in books as well as law in action. In chapter IV consequences of vulnerability, dementia and law will be discussed and analyzed by using Martha Albertson Fineman's vulnerability theory. The chapter ends with the recommendation of the need for legal and policy alternatives that can provide cognitively impaired persons with greater assistance in decision-making. We also stress the need for further multidisciplinary studies in this field.

The proportion of people in the world over the age of 60 is expected to increase rapidly in the coming years, from 12% in 2015 to 21% by 2050.[1] As the population grows older, all countries will need to find ways to adjust to different aspects of an ageing population. One such aspect is that longer life is associated with increased prevalence of chronic diseases and impairments. Dementia is a major and increasing cause of disability among older persons worldwide.[2] It may cause deterioration in memory, thinking, behavior, and the ability to perform everyday activities. Causing disability and dependency for so many people, it has a significant impact on many individuals, families, communities and societies around the world. In Sweden as well as in other countries with developed social welfare systems, the increasing number of persons with dementia also means a larger burden of providing individual access to medical as well as social care services for this growing segment of the population.

The topic of this Article is the dilemma that social workers face when they are required, under the terms of Swedish legislation, to determine whether

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[1] U.N. Dep't of Econ. & Soc. Affairs, Promoting Inclusion through Social Protection, Rep. on the World Social Situation, at 47, U.N. Doc. ST/ESA/366, Sales No. E.17.IV.2 (2018).

[2] World Health Organization (WHO), Global Action Plan on the Public Health Response to Dementia 2017–2025, 2 (2017), https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf.

persons suffering from dementia are to be granted support for homecare services under the Social Services Act.[3] The Act puts a strong emphasis on consent and self-determination, which sometimes gives rise to difficult dilemmas in the conduct of social work. Swedish legislation in this area stresses the autonomy of individuals and their consequent capacity to give or withhold their consent to services — with no legal authority being granted to social workers to decide on their behalf. In practice, however, some persons with dementia lack the capacity to make their own decisions. Cognitively impaired persons may have a legal guardian in Sweden, but it is quite unusual. No specific statistics are available, but only 10% of those with some sort of legal guardian suffer from dementia, although such persons make up one of the larger groups among the cognitively impaired in Sweden.[4] From these general statistics we can conclude that many persons with dementia in Sweden do not have a legal guardian. In practice, legal guardians are primarily assigned to persons who lack relatives or who possess large fortunes.[5] This situation raises general issues of vulnerability within care systems for persons with dementia. Although we are challenging the Swedish system in this Article, we believe this is a good case study with regard to other countries. Because dementia is one of the major causes of disability in later life around the world, health issues for this group is a major field of responsibility for social workers in elder care.

In social welfare law as well as in other areas of the law, the term vulnerability is commonly used to categorize a certain portion of the population on the basis of aspects of the human condition which are commonly considered "undesirable," such as weakness, poverty, loneliness, dependency, or even old age. We mean to challenge this perception. Instead, we propose, vulnerability should be seen as a universal state of being, and not as something deriving from a certain age or similar trait. More precisely, we draw on Martha Albertson

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[3] We discuss this issue of consent and vulnerability in connection with an interdisciplinary (law/social work) research project which we are undertaking, "Who's voice? Care management and dementia." The project is financed by The Kamprad Family Foundation for Entrepreneurship, Research & Charity (2018).

[4] SWED. JUST. DEP'T, SOU 2004:112, FRÅGOR OM FÖRMYNDARE OCH STÄLLFÖRETRÄDARE FÖR VUXNA [QUESTIONS ABOUT GUARDIANS AND DEPUTIES OF ADULTS] (2004).

[5] There were 68,548 limited guardianships and 12,284 legal administrators in 2017 in Sweden. There is no national documentation of reasons for guardianship. LÄNSSTYRELSEN [COUNTY ADMINISTRATIVE BOARD], ÖVERFÖRMYNDARSTATISTIK [SUPERVISORY STATISTICS], (2018) (Swed.), https://overformyndarstatistik.lansstyrelsen.se/Statistik.

Fineman's vulnerability theory.[6] This theory can be used, we contend, to stake out an alternative path both for researchers and for policymakers dealing with social welfare issues. Fineman's approach to questions of vulnerability and dependency offers a useful way of addressing the rights of persons with dementia — one that is not based on categories of age, gender, or health.

Persons with dementia are in many ways trapped in their categorization as a "vulnerable group," as traditionally understood. The Western legal tradition presupposes a subject that is independent, self-sufficient and able to pursue his or her own interests. When this ideal is transferred to persons with different degrees of dementia who may have declining abilities in these regards, they are often stigmatized as a group and seen as vulnerable, irrespective of their individual abilities.[7] Stigmatization becomes obvious when demographic changes are occurring and policymakers need to react accordingly. However, the debate often tends to reflect certain stereotypes of what individuals with dementia are like, and what they need. Such portrayals can lead to objectively unfounded views and preconceived assumptions as regards a person's needs and behavior. For example, if there is a lack of information about a person, knowledge gaps can be filled in with general stereotypes instead of searching for information about the person from him- or herself or from the family. The conceptualization of such persons as a group must therefore be problematized.

Along the lines of vulnerability theory, we see ageing and declining health more as *part of life* than as traits delineating any distinct group of persons. Persons with dementia, like everyone else, are people who live with changing needs and circumstances on a daily basis. This makes the needs of these individuals as complex and varied as they themselves are. Ageing and declining health are both basic human conditions, which necessarily influence the relationship between the state and the individual in a variety of ways. However, ageing and declining health furnish no quantitative basis for measuring the needs and capacities of individuals. For example, age classifications — such as age limits based on expectations of "normal ageing"

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[6] Martha Albertson Fineman is the Robert W. Woodruff Professor of Law at Emory Law School, Atlanta. She is the founder and director of the Vulnerability and the Human Condition (VHC) Initiative and the Feminism and Legal Theory Project. Fineman's vulnerability theory is the basis for several research centers in Europe and the United States, including the VHC Initiative at Emory, the VHC hub at the Center for Law & Social Justice at Leeds University, and the Law and Vulnerability Research Program at Lund University. The theory is also an integrated part of the Norma Elder Law Research Environment at Lund University.

[7] Titti Mattsson & Mirjam Katzin, *Vulnerability and Ageing*, *in* Elder Law: Evolving European Perspectives 113 (Ann Numhauser-Henning ed., 2017).

— are often too coarse for determining who should and who should not have access to certain benefits and services.[8] The situation is the same with health classifications. Health matters must be dealt with on an individual basis, and there is no such thing as "normal health." Our arguments in this Article specifically apply to persons with dementia. Dementia is an illness that can take many different shapes depending on its cause. Common traits are loss of memory and other mental abilities severe enough to interfere with daily life, caused by physical changes in the brain. Alzheimer's is one common type of dementia, but there are many other kinds. As a result, the needs and dependencies of persons suffering from dementia may vary considerably.

In this Article, we argue that a solid overarching theoretical framework is needed if a fruitful discussion is to be possible about the legal considerations arising in connection with the needs and difficulties of persons with dementia, and how these relate to organizational and structural circumstances in society. Fineman argues that vulnerability — the universal and inevitable aspect of the human condition — should be a starting point for legislation. From such a standpoint follows the need for a responsive state for all, and not just for some specific groups or individuals. A vulnerability analysis emphasizes our interdependency within social institutions and the need for public responsibility. It underscores that equal opportunity can be achieved only by offering different ways in which situations of dependency can be overcome by legislation or practice.[9] The theory also emphasizes the need for respecting difference and diversity among persons and during persons' lifespans.[10] One way to put a focus on the complexity of human needs is to highlight universal concerns for every human being, such as influence and dignity. When it comes to the rationale for taking into consideration the individual capacity and the need for specific care of each person with dementia, according to vulnerability theory, the state has to take responsibility also for people who have difficulties or who are unable to put forward their concern themselves.[11]

Vulnerability theory has value as an overarching framework for creating and evaluating public policy and regulation. Because of its focus on individually shaped tools of resilience against the inevitable vulnerability, it is useful

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[8] Titti Mattsson, *Age, Vulnerability and Disability*, *in* AGEISM, AGEING AND THE LAW: EUROPEAN PERSPECTIVES ON THE RIGHTS OF OLDER PERSONS (Israel Doron & Nena Georgantzi eds., 2018).

[9] MARTHA ALBERTSON FINEMAN, THE AUTONOMY MYTH: A THEORY OF DEPENDENCY (2004).

[10] Martha Albertson Fineman, *The Vulnerable Subject: Anchoring Equality in the Human Condition*, 20 YALE J.L. & FEMINISM 1, 3 (2008).

[11] *Id.*

for our discussion of ways to fulfill the needs of such a diversified group in society as persons with dementia. Using the theory as the framework for our discussion, we contend that policymakers should not apply a group-oriented approach based on age or diagnosis to individuals with dementia. Instead of cementing solidarity, such an approach can lead to the stigmatization of certain persons as a "vulnerable group," leaving them without strong social rights or the ability to participate in shaping the measures undertaken for their support. Our argument, therefore, is that the unique needs and wishes of each individual ought to provide the main guideline for public discussion about public services for persons who lack full capacity.

The situation in Sweden is interesting because current legislation in this country puts an extremely strong stress on the self-determination of individuals, whether or not they possess a legal guardian or have other legal assistance. Research has shown that if explicit consent is required on all questions regarding basic living conditions, many persons with dementia will risk being neglected or even be endangered, and their family may be faced with difficult situations.[12] This strong emphasis on self-determination would appear to be an unusually liberal feature for a welfare state generally classified as social-democratic.[13] An in-depth discussion is therefore needed in Sweden about the relationship between the individual, the family, the welfare state, and the legislative framework in matters of self-determination, dependence, and legal guardianship.

In this Article, we discuss the practical consequences that follow from the legal requirements for consent contained in Swedish social legislation, as well as the impact of the rules for legal guardianship set out in the Child and Parents Code. We focus on the effect of these provisions on the situation of persons with dementia. We do this from both a legal and a social-work perspective, and with an eye to both the law in the books and the law in practice. We take our starting point in certain dilemmas that arise in connection with consent, autonomy, and protection for persons with dementia.

If a person suffering from dementia lacks the capacity to give or withhold consent, how is the responsible social worker to handle the situation? We illustrate this predicament with some current research findings and proceed

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[12] *See* LOTTIE GIERTZ, ULLA MELIN EMILSSON & MARIE ALBERTSSON, STÄLLFÖRETRÄDARSKAP OCH DEMENS [GUARDIANSHIP AND DEMENTIA] (Linnaeus University, 2019) (Swed.); Lottie Giertz, Ulla Melin Emilsson & Emme-Li Vingare, *Family Caregivers and Decision-Making for Older People with Dementia*, 41 J. SOC. WELFARE & FAM. L. (2019).

[13] *See* Marta Szebehely & Gabrielle Meagher, *Nordic Eldercare — Weak Universalism Becoming Weaker?*, 28 J. EUR. SOC. POL'Y 294 (2018).

to analyze it using vulnerability theory. The core problem concerns the tension between two possible outcomes. On the one hand, ensuring the right of persons with dementia with everyday living on a voluntary basis. On the other, running the risk that such persons will find their needs seriously neglected, due to their diminished capacity and the Act's heavy emphasis on obtaining their consent.

By focusing on the situation faced by persons with dementia, we hope to illustrate some of the problems arising in connection with legislation that assumes — more or less unconditionally — full legal capacity on the part of all persons. The societal goals of self-determination and autonomy for all persons are central in the legal systems of most countries, and they are very important for all democratic societies. Yet these goals can also be problematic at times, particularly in relation to cognitively impaired individuals who need support and who lack a decision-making assistant or representative. The question then arises: how are good living conditions to be ensured in the case of persons who lack the capacity to give or withhold their consent?

I. Vulnerability and the Family

According to Martha Albertson Fineman, the general belief in autonomy for all reflects a general social-liberal discourse based on individualism, autonomy, and rights claims by "vulnerable groups."[14] Yet such a belief, she argues, cannot always be sustained.[15] Her account is based on an analysis of American legislation, but it is also helpful for understanding some of the problems with the Swedish welfare system.

According to Fineman, it is time to focus less on equal treatment and equal rights, and more on the universal conditions of human life. Being vulnerable at various points in life is common to all of us. This, Fineman writes, is an "inevitable" feature of the human condition.[16] As children we were vulnerable and dependent on others, and as elders we shall be again. We are also equal in the sense that we run various risks throughout our life, e.g., unemployment, illness, divorce, accidents.[17] Fineman contends that if we adopt this lifecycle perspective — with its point of departure in our common vulnerability — we will better appreciate the need to build a legal and social order in which our common responsibility for everyone's needs and wellbeing is taken

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[14] Fineman, *supra* note 9.

[15] *See id.*

[16] *See id.* at 57-70.

[17] *See* Fineman, *supra* note 10, at 9.

seriously. This is a responsibility which must be borne by social institutions and individuals alike.[18]

The prevailing legal system in the West holds out the autonomous subject as the model for the legal subject. Such an individual is able to make free and autonomous choices, to speak for him/herself, to assess all possible options, and to make rational decisions. However, Fineman contends, this is a flawed conception of the human subject, for it fails to take into account all those persons who for different reasons are dependent on others in order to live their lives.[19] The ability to live independently of other persons and of social institutions may be limited by age, illness, family situation, or economic condition.[20] Nonetheless, even those dependent on others have the right to communicate their wishes and needs. However, there are also individuals who — besides being completely dependent on others for daily support — are in need of someone to speak for them on many matters of daily life.

The family as a private field and the welfare system as a public one are the two main fields where our vulnerability is either hidden or revealed. The organization of the family and its responsibilities privatizes human vulnerability. It is the family that often is responsible for protecting its members — such as children and the elderly — at the beginning and end of life. Fineman describes such dependence as "inevitable," due to the basic conditions of human life. The duty to provide care which arises from this dependence is often thought to fall mainly on the family, rather than on society at large.[21]

In Sweden, the duty to provide care at the beginning of life is largely shared between public institutions and the family. For example, we have free and general healthcare for children, extensive childcare, and free school for everyone up to the age of 19.[22] In the United States, by contrast, the care of children is largely the responsibility of the family. The "others" on whom American children are dependent, therefore, are largely the other members of their family.

At the other end of life, we all depend sooner or later on support from others. Over the course of the last two decades, however, the elder-care system in Sweden has changed: the national goal of relieving families of

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[18] *See id.*

[19] *See* Marta Albertson Fineman, *'Elderly' as Vulnerable: Rethinking the Nature of Individual and Societal Responsibility*, 20 Elder. L.J. 102 (2012).

[20] *See id.*

[21] *See* Marta Albertson Fineman, The Neutered Mother, the Sexual Family and Other Twentieth Century Tragedies (1995).

[22] Hälso-och Sjukvårdslag [Health and Medical Services Act] (1982:763) (Swed.); Skollag [The Education Act] (2010:800) (Swed.)

legal responsibility for their older members has given way to a new trend, in which reliance on support from the family is central in practice once again.[23] In 1956, the obligation of adult children to provide care for their parents was removed from social legislation. From the 1960s up to the late 1980s, moreover, elder care was expanding, with 53% of persons aged 80 years or older being furnished with homecare or residential housing by 1990. Since then, however, the size of the sector has diminished, and elder care is now the responsibility of the family to a much greater extent.[24] Between 1990 and 2005, for example, the number of places in residential housing fell, as did the number of persons with homecare (even as the number of older persons rose).[25] Today, 70% of elder care is provided by family members, mainly spouses and adult daughters.[26]

Changes of this kind, Fineman argues, hide the means by which care is provided, and the needs of both care recipients and other family members are neglected as a result. The responsibility for care is transferred from the public to the private sphere — to the family.[27] In Fineman's terms, then, Swedish elder care is now largely private once again. The welfare state and the family as institutions are both visible elements in the organization of care for older people, but there are underlying structures and assumptions here that remain hidden. Fineman argues that these hidden structures are difficult to assess if we only focus on so-called vulnerable groups or individuals. However, if we consider the whole community instead, and create institutions that address the vulnerabilities common to us all at different stages of life, we will be able to ensure just and fair living conditions in a more comprehensive way than we do today. The image of all individuals as autonomous and independent is not realistic.

We turn now to the relationship between persons with dementia, their families, and professionals from the social services. More precisely, we present some of our research findings regarding this relationship in the light of current legislation.

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[23] *See* Petra Ulmanen & Marta Szebehely, *From the State to the Family or to the Market? Consequences of Reduced Residential Eldercare in Sweden*, 24 INT'L J. SOC. WELFARE 81 (2015).

[24] MIRJAM KATZIN, *Rätten till Äldreomsorg* [*The Right to Elderly Care*], *in* ÄLDRERÄTT: ETT NYTT RÄTTSOMRÅDE [ELDER LAW: A NEW LEGAL FIELD] (Titti Mattsson & Ann Numhauser-Henning eds., 2017) (Swed.); Szebehely & Meagher, *supra* note 13.

[25] KATZIN, *supra* note 24.

[26] ANN-BRIT SAND, ANHÖRIGA SOM KOMBINERAR FÖRVÄRVSARBETE OCH ANHÖRIGOMSORG [RELATIVES WHO COMBINE ACQUISITION AND FAMILY CARE] (2010) (Swed.).

[27] FINEMAN, *supra* note 21.

II. THE SWEDISH CASE STUDY

Our starting point is that the difficulties faced by persons with dementia in the Swedish welfare state illustrate the problems with a system that always assumes autonomous individuals, both in law and in practice. In our review of several examples below, we discuss dementia, decision-making, and Swedish legislation from the standpoint of both law and social work. We believe that a cross-disciplinary approach can help us better address the rights, interests, and needs of older people, of their families, and of professionals in the social-welfare system; and that it can throw light on the problems faced by ageing societies in general. Martha Fineman's socially based theory supports such approach. Combining law with empirical research with this model may explain how law impacts on different groups or individuals. Thus, using her legal theory may open up opportunities to use research in the social sciences to study the human condition in law.

The ageing of populations has a profound impact on the incidence of dementia in all countries, including Sweden. Dementia is characterized by a progressive deterioration in cognitive ability, and in the capacity for decision-making and independent living. The cognitive impairment associated with dementia increases the need for assistance with everyday activities and the making of decisions.[28] Thus, people with dementia are some of the most disadvantaged and powerless members of our society.[29]

Most people in the world who suffer from dementia are cared for at home by a family member.[30] Several studies have examined the views of caregivers and family members about various medical decisions at the end of life, such as whether life-sustaining treatment and resuscitation should be provided.[31] Few studies have examined the decision-making processes involved when a family member with dementia is moved from his or her own home to

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[28] *See* Martin Prince et al., *The Global Prevalence of Dementia: A Systematic Review and Meta-Analysis*, 9 ALZHEIMER & DEMENTIA 63 (2013).

[29] *See* Rosie Harding, *Legal Constructions of Dementia: Discourses of Autonomy at the Margins of Capacity*, 34 J. SOC. WELFARE & FAM. L. 425 (2012).

[30] *See* Kritika Samsi & Jill Manthorpe, *Everyday Decision-Making in Dementia: Findings from a Longitudinal Interview Study of People with Dementia and Family Carers*, 25 INT'L PSYCHOGERIATRIC 949 (2013).

[31] *See* Kathryn Lord, Gill Livingstone & Claudia Coper, *A Systematic Review of Barriers and Facilitators to and Interventions for Proxy Decision-Making by Family Carers of People with Dementia*, 27 INT'L PSYCHOGERIATRIC 1301 (2015); José Miola, *Proxy Decision-making*, *in* THE LAW AND ETHICS OF DEMENTIA 149 (Charles Foster, Jonathan Herring & Israel Doron eds., 2014).

residential housing.[32] Scholars emphasize the need for further research on the relationship from a legal point of view between persons with dementia and the other members of their family.[33]

A. The Swedish System of Elder Care for Persons with Dementia

In general, Nordic welfare systems are known for offering more in the way of local elder-care services than other European welfare systems.[34] Elder care in Sweden is a responsibility of the municipality, and it is publicly funded. Grown-up children and other family members are not responsible for the care of an adult family member. Instead the Social Services Act obliges local authorities to take the overall responsibility for the rights and wellbeing of older persons in need of health, social and economic assistance, including providing home-based and residential care to adults who are assessed as needing such services. [35]

Swedish social-welfare legislation is largely based on the right of autonomous and independent individuals to make their voice heard and to give or withhold their consent. This is true of the Health and Medical Services Act (ch. 5 para. 1), the Social Services Act (ch. 1 para. 1), the Child and Parents Code (ch. 11 para. 4), and the Act regulating Support and Service to Persons with Certain Functional Disabilities (paras. 4-6).[36] In 2009, the Swedish parliament added a provision to the latter stating that "municipalities are obliged to offer support to

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[32] *See* Jeanne Tyrell, Nathalie Genin & Michele Myslinsky, *Freedom of Choice and Decision-Making in Health and Social Care: Views of Older Patients with Early-Stage Dementia and Their Carers*, 5 Dementia 479 (2006).

[33] *See, e.g.*, Eva Ryrstedt, *Dementia and Autonomy*, *in* Elder Law: Evolving European Perspectives 358 (Ann Numhauser Henning ed., 2017); Beverley Clough, *Disability and Vulnerability: Challenging the Capacity/Incapacity Binary*, 16 Soc. Pol'y & Soc'y 469 (2017).

[34] *See* Ingrid Jönsson et al., *The Implementation of Elder-Care in France and Sweden: A Macro and Micro Perspective*, 31 Aging & Soc'y 625 (2011); Szebehely & Meager, *supra* note 13; Klaus Haberkern & Marc Szydlik, *State Care Provision, Societal Opinion and Children´s Care of Older Parents in 11 European Countries*, 30 Aging & Soc'y 299 (2010).

[35] Socialtjänstlagen [The Social Services Act] (2001:453) ch. 2 ¶ 1, ch. 5 ¶¶ 4-6 (Swed.).

[36] Hälso-och Sjukvårdslag [Health and Medical Services Act] (1982:763) (Swed.) ch. 5 ¶ 1; Socialtjänstlagen [The Social Services Act] (2001:453) ch. 2 ¶ 1; Föräldrabalk [Fb] [Child and Parents Code] (1949:381) ch. 11 ¶ 4; Lag om Stöd och Service till Vissa Funktionshindrade [Support and Service to Persons with Certain Functional Disabilities Act] (1993:387) ¶ 6 (Swed.).

persons caring for people with chronic illnesses, older people, or people with functional disabilities."[37] According to the Act, all measures should be based on the consent of care recipients, and the measures undertaken on their behalf are to be devised and implemented together with them. In 2010, the National Board of Health and Welfare published the first national guidelines for the care of people with dementia. They were updated in 2017.[38] The guidelines address all stages of care for persons suffering from dementia, from examination and diagnosis to end-of-life care. They give advice to professionals on various aspects of their work, and they are aimed at political decision-makers as well. They focus on both the medical and the social aspects of dementia, and they stress that care must be person-centered.

The municipalities are responsible for providing home-based care for older persons and individuals with disabilities, as well as care at general or specialized nursing homes. They are also required to support family caregivers.[39] By contrast, screening, diagnosis, and medical treatment are the responsibility of the healthcare system supervised by the county councils.[40] Due to the strong emphasis on local self-government in Sweden, it is up to the local authorities to decide what kind of services to offer. The dementia care provided may thus vary between municipalities. Some offer special daycare centers and short-term nursing homes for persons with dementia, among other things to support family caregivers. In most municipalities (though not all), there are residential homes with special dementia wards and registered dementia nurses.

Another characteristic feature of elder care in Sweden is the shift from institutional to home-based care.[41] Most municipalities seek, in accordance with the right to independent living,[42] to enable older persons to continue to

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[37] Lag om Ändring i Socialtjänstlagen [Amendments to the Social Services Act] (SFS 2009:549) (Swed.).

[38] SOCIALSTYRELSEN [MINISTRY OF HEALTH AND SOCIAL AFFAIRS], NATIONELLA RIKTLINJER FÖR VÅRD OCH OMSORG VID DEMENSSJUKDOM — STÖD FÖR STYRNING OCH LEDNING [NATIONAL GUIDELINES FOR CARE OF AND SERVICE TO PEOPLE WITH DEMENTIA] (2017) (Swed.).

[39] SOCIALTJÄNSTLAGEN [THE SOCIAL SERVICES ACT] (2001:453) (Swed.)

[40] HÄLSO-OCH SJUKVÅRDSLAG [HEALTH AND MEDICAL SERVICES ACT] (1982:763) (Swed.)

[41] SWED. SOC. DEP'T., DS 2003:47, PÅ VÄG MOT EN GOD DEMENSVÅRD: SAMHÄLLETS INSATSER FÖR PERSONER MED DEMENS-SJUKDOM OCH DERAS ANHÖRIGA [ON THE ROAD TO SATISFACTORY DEMENTIA CARE: STATE EFFORTS FOR PEOPLE WITH DEMENTIA AND THEIR RELATIVES] (2003) (Swed.).

[42] Article 19 of the Convention of the Rights of Persons with Disabilities recognises the right of all persons with disabilities, regardless of age and impairment, to live independently and be included in the community.

live at home while receiving care. Between 2001 and 2012, the number of older persons in institutional care fell by 24%.[43] The right to independent living presupposes adequate assistance and support, access to a range of community support services, in-home support and residential services if care recipients are to stay safe, healthy, and confident. Services for people with dementia vary across municipalities; however, all municipalities must provide basic elder care.

B. Dementia and the (In)capacity to Give or Withhold Consent to Services

As populations age, more and more people face the prospect that a parent or spouse with dementia will need assistance with personal care and the tasks of daily life.[44] This trend highlights the need for a discussion on how to ensure that individuals who lack the ability in practice to give or withhold their consent receive the services to which they are entitled. Furthermore, unlike their counterparts in many other parts of the world, families in Sweden do not have any legal mandate to make critical life decisions for those of their adult members who lack the cognitive capacity to make such decisions on their own.

Moreover, social workers in Sweden lack the legal authority to make decisions on behalf of persons suffering from dementia without their consent. A limited number of persons may be assigned a substitute decision-maker by a court. According to the Child and Parents Code, there are two types of legal guardian for adults suffering from dementia.[45] The most common is the limited guardian (*god man*), who provides help with decision-making. The limited guardian only has a supportive role as regards decision-making, i.e., to help and support. The person with dementia does not lose his or her legal capacity to act. Only if the person's health condition is such that he or she has lost the legal capacity to act may the limited guardian act on behalf of the supported person. The other type of guardian — the legal administrator (*förvaltare*) — acts as a substitute decision-maker. A legal administrator has greater authority and appropriates the subject's decision-making powers, thus acting in his or her place. The appointment is limited by the court to what is considered necessary. Thus, the person retains his or her legal capacity to act in areas of life left outside that scope by the court.

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[43] *See* Ulmanen & Szebehely, *supra* note 23.

[44] *See* Israel Doron, *The Demographics of Dementia*, *in* The Law and Ethics of Dementia, *supra* note 31, at 15.

[45] Föräldrabalk [Fb] [Child and Parents Code] (SFS 1949:381) ch.11 ¶ 4, 7 (Swed.).

The Child and Parents Code is not clear about whether a limited guardian can apply for support measures without consent from the client.[46] Due to their highly unclear legal status where decision-making is concerned, then, limited guardians are not currently able to ensure a decent standard of living for cognitively impaired persons.

There is also the possibility of arranging a general power of attorney, mainly in connection with the person's financial situation.[47] According to new legislation in July 2017, an alternative possibility is a durable power of attorney.[48] However, this legislation too relates largely to property and financial affairs, rather than to social services or healthcare. There is still a gray zone of applicability here that has not yet been tested in court.

Due to the very limited provision for substitute decision-making in Sweden at present, many who suffer from dementia in that country do not have legal guardians to assist them in contacts with the authorities. Thus, decisions on service for people with dementia must often be made by persons who do not have legal authority. Contacts with the social services in Sweden are based on the principle of individual self-determination, and on the associated assumption that care recipients have the capacity to grant or withhold consent. This means that the family is often the last resort in practice for assistance with decision-making, even though its members lack the legal capacity to decide on behalf of the person in question. As the number of persons with dementia is rapidly rising in Sweden, so too is the number of families whose members must cope with the current restrictions on assistance from the social services in this area.

III. THE LAW AND PRACTICE IN COMBINATION

Over several years, a research team in which one of us took part conducted interviews with people suffering from dementia, their relatives, and professionals

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[46] THERESE FRIDSTRÖM MONTOYA, LEVA SOM ANDRA GENOM STÄLLFÖRETRÄDARE: EN RÄTTSLIG OCH FAKTISK PARADOX [TO LIVE LIKE OTHERS THROUGH LEGAL REPRESENTATION: A LEGAL AND FACTUAL PARADOX] (2015) (Swed.).

[47] LINUS BROSTRÖM & MATS JOHANSSON, STÄLLFÖRETRÄDARSKAP I VÅRD OCH OMSORG [GUARDIANSHIP IN CARE AND SOCIAL SERVICES] (2012) (Swed.); TORBJÖRN ODLÖW, STÄLLFÖRETRÄDARE FÖR VUXNA: KAMRER ELLER HANDLEDARE? [GUARDIAN OF INCAPABLE ADULTS: ACCOUNTANT OR SUPERVISOR?] (2005) (Swed.).

[48] LAG OM FRAMTIDSFULLMAKTER [ACT OF FUTURE POWER OF ATTORNEY] (SFS 2017:310) (Swed.); Proposition [Prop.] 2016/17:30 Framtidsfullmakter — en Ny Form av Ställföreträdarskap för Vuxna [Future Proxies — A New Form of Representation for Adults] (Swed.).

in municipal dementia care. The purpose of the interviews was to ascertain the nature of the contacts between the three groups, with particular attention to questions of consent, decision-making, and living conditions for persons with dementia.[49] The results presented below come from two separate interview studies. One consisted of interviews with 292 persons: 88 individuals with dementia living at home; 58 such persons living in special accommodations; and an equal number (146) of their relatives. The other study consisted of interviews with 14 people suffering from dementia, and 19 of their relatives. Some relevant findings from the two studies are summarized below.

The interviews demonstrate, on the one hand, that some persons with dementia find their quality of life to be high, no matter how or where they live. They are also pleased with the contact they have with their relatives. Family members who serve as caregivers, on the other hand, point to the many complex and difficult situations that arise in everyday life. For example, many persons with dementia who live alone have serious difficulty running their household and managing their personal hygiene. Yet they may be satisfied with the situation, and may not consider their faulty memory as regards medicine or food to be problematic. They may not understand how to wash, clean, or shop. Family members also mention some dangerous situations, e.g., when their relative drives a car, or fails to perceive a fire danger, or gets lost in the forest or in the city.

These examples show how hard it is to maintain a high quality of life for a person with dementia if he/she resists help despite acutely needing it. When the family caregiver tries to persuade the person to seek help, he/she usually rejects the idea. Furthermore, even if the social worker manages to arrange a meeting — often with the person in question and a family member — the welfare office still cannot legally offer support unless the person with dementia applies personally and gives his or her consent. If said person claims that he or she can shop, cook, wash, and manage medicine, the office typically takes this as tantamount to consent to the current arrangement.

In support of this approach, the social workers in our interviews often cited the emphasis on individual self-determination in the Social Services

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[49] GIERTZ, MELIN EMILSSON & ALBERTSSON, *supra* note 12; Connie Lethin et al., *Persons with Dementia Living at Home or in Nursing Homes in Nine Swedish Urban or Rural Municipalities*, 7(2) HEALTHCARE 80 (2019). The research projects: “Living with Dementia, Care and Social Services” (financed by The Kamprad Family Foundation 2013-121) and “Guardianship for Older Persons with Dementia” (financed by FORTE 2015-01132).

Act.[50] Said legislation, in their understanding, has to be interpreted strictly, with support allowed only if the individual him- or herself has applied for it personally. However, according to the family members we interviewed, this can lead to neglect and a low quality of life for the person in question and sometimes even endanger his or her health and life. Family caregivers found it hard to understand how social workers could ask for decisions about social support from people incapable of making decisions about such things as money, medicine, food, or clothes. These findings match the quite nuanced discussion of capacity found in Clough as well as Ryrstedt.[51]A relational starting point to consent and capacity would have a supportive and collaborative approach involving family caregivers in the complexity of decision-making.

IV. Discussion

Daily life for an individual with dementia involves a long list of decisions, as it does for all human beings. These may be everyday decisions about clothing, breakfast, and leisure activities, or more significant decisions about health-related issues like medicine and exercise. Individuals must make their own decisions on such matters of everyday life in the home. For many or most people, such decisions regarding health and wellbeing form a natural part of daily life.[52] Decisions about basic conditions like place of residence may also arise. But for those who suffer from illness, injury, or age-related disability, all such decisions may be difficult or even impossible to make. A person's capacity to make decisions can be undermined or even eliminated by external brain damage, a disease such as dementia, or other debilitating conditions.[53]

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[50] Ann-Charlotte Nedlund & Annika Taghizadeh Larsson, *To Protect and to Support: How Citizenship and Self-Determination are Legally Constructed and Managed in Practice for People Living with Dementia in Sweden*, 15 Dementia 343 (2016).

[51] Giertz, Melin Emilsson & Albertsson, *supra* note 12; Clough, *supra* note 33; Ryrstedt, *supra* note 33.

[52] Ulla Hellström Muhli, Bridging Perspectives — A Study of Need Assessment Dialogues in Elderly Orient Social Work (Dec. 11, 2003) (unpublished Ph.D. thesis, Gothenburg University) (on file with author).

[53] Gary Sinoff & Natalia Blaja-Lisnic, *Advance Decisions and Proxy Decision-Making in the Elderly: A Medical Perspective*, *in* The Law and Ethics of Dementia, *supra* note 31, at 97.

Persons with extensive limitations in this regard may need assistance from a substitute decision-maker in their contacts with the social services.[54] Support for such people is formalized in different ways in different countries.[55] Legal representatives such as trustees, limited guardians, or legal administrators may be appointed in order to ensure due process for persons whose ability to make decisions is impaired.

The legal trend in recent decades in Sweden has been to move away from protection towards greater autonomy.[56] This approach is also founded in the UN Convention on Rights for Persons with Disabilities (CRPD), which Sweden ratified in 2008. Interventions in the life of such persons, the Convention enjoins, must be as minimal as possible. The norm should be assisted rather than substitute decision-making.

However, one consequence of this in practice is that some persons suffering from mental impairment do not get the support to which they are entitled until the very late stages of their illness (if indeed even then). This can easily happen to persons without a legal guardian (in Sweden a legal administrator) who is empowered to apply for such support. Where limited guardians are concerned, it is unclear as yet whether they have the power to make such decisions in Sweden. Accordingly, even persons with a limited guardian may not get the assistance they need if they are to enjoy good living conditions. As for cognitively impaired persons without any kind of legal guardian, their situation is of course problematic, as they must consent formally to all services in order to get them. Current legislation makes it difficult, then, to deal with a situation where a person needs help but lacks the mental capacity to seek out such help by him- or herself.[57]

The rights and freedoms of persons with dementia, then, are still very fragile in Sweden.[58] Further investigation is needed if protection, due process, and good living conditions are to be ensured for such people. The demand for due process is a fundamental value of public law, and legal provisions on both the national and the international level stress its centrality in all interventions by

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[54] Ryrstedt, *supra* note 33; Fridström Montoya, *supra* note 46; Walter C. Schmidt, *Proxy Decision-Making: A legal Perspective*, *in* The Law and Ethics of Dementia, *supra* note 31, at 311.

[55] Israel Doron, *Elder Guardianship Kaleidoscope — A Comparative Perspective*, 16 Int'l J.L., Pol'y & Fam. 368 (2002); Doron, *supra* note 44.

[56] Ryrstedt, *supra* note 33.

[57] Annika Taghizadeh Larsson & Johannes Österholm, *How Are Decisions on Care Services for People with Dementia Made and Experienced? A Systematic Review and Qualitative Synthesis of Recent Empirical Findings*, 26 Int'l Psychogeriatrics 1849 (2014).

[58] Ryrstedt, *supra* note 33; Tyrell, Genin & Myslinsky, *supra* note 32.

society into the life of individuals. In this Article, we understand due process to include demands not just in the formal sense of the term,[59] but also, for ethically reasonable decisions, in the material sense of the term.[60] It is fundamental to due process that laws be clear and that their effects be foreseeable, and also that they make for fair, reasonable, and ethical decisions. As we have seen, the legal situation is unclear as regards the extent to which assisted or substitute decision-making is allowed in matters having to do with the basic living conditions of persons with dementia. The effect of this lack of clarity — on the prerogatives of social workers and most crucially, of course, on the living conditions of their clients — is a very serious matter. According to the Social Services Act, it is the social worker who bears the final responsibility (*yttersta ansvar*) for the individual who needs help. The legal responsibility of the former to improve the living conditions of the latter is very clear, but there is a legal vacuum concerning how such responsibility is to be carried out without the client's explicit consent. Nor is this a question of interest only to a demarcated "vulnerable group"; rather, it concerns a vulnerable condition shared by all.

A critical discussion is ongoing internationally about capacity, autonomy, and cognitive impairment.[61] Some countries have seen efforts to find legislative tools for these kinds of situations. The question of legal guardianship and other forms of representation is an issue of global interest in different fields.[62] Some countries have legislation for proxy decision-making, enabling family caregivers to make decisions on behalf of relatives with diminished mental capacity; however, such legislation differs between countries. In England and Wales, the Mental Capacity Act 2005 allows social workers under certain conditions to make decisions regarding health and living conditions on behalf of incapacitated clients.[63] Like its Swedish counterpart, this legislation takes its starting point in the presumption that people can make their own decisions. However, it also provides for assisted decision-making on a case-by-case basis by the social worker, with all possible avenues for assisting a person's

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[59] Josef Zila, *Om Rättssäkerhet* [*On Legal Security*], 75 SVENSK JURISTTIDNING 284 (1990) (Swed.).

[60] LOTTA VAHLNE WESTERHÄLL, RÄTTSSÄKERHETSFRÅGOR INOM SOCIALRÄTTEN: 10 PERSPEKTIV [LEGAL SECURITY ISSUES IN SOCIAL RIGHTS: 10 PERSPECTIVES] (2002) (Swed.).

[61] Anna Arstein-Kerslake & Ellionoir Flynn, *The Right to Legal Agency: Domination, Disability and Protections of Article 12 of CRPD*, 13 INT'L J.L. CONTEXT 22 (2017).

[62] Schmidt, *supra* note 54.

[63] Harding, *supra* note 29.

decision-making to be explored before he or she is declared incompetent.[64] The Mental Capacity Act also allows relatives to be given lasting power of attorney to make medical or social decisions.[65]

There has been a recurrent international debate about the need for complementary or alternative ways of assisting decision-making by older people and individuals suffering from cognitive impairment. It bears emphasis; however, that substitute decision-making involves the risk of limiting autonomy and undermining fundamental rights.[66]

In Fineman's (2004) terms, the "myth of autonomy" has been taken so far in Sweden that the most dependent persons found in our society today are those whose decision-making ability is limited, whose capacity to assess consequences is weak, and whose cognitive impairment renders them unable to grasp or process crucial personal information. These include persons with dementia, with an intellectual disability, or with other kinds of mental disabilities. If one suffers from a lifelong disability, such as intellectual impairment, then the myth of total autonomy may be of limited relevance throughout one's life. If one has an age-related disability, such as dementia, then the relevance of the autonomy-for-all ideal is at its nadir at the end of life. Such an ideal has to be balanced by support structures, and by an individualized assessment of the needs of different people. The legal system must be able to take account of different individuals' way of expressing their will, and yet must be capable too of securing their right to support and protection when their ability to do so fails.

One way to take proper account of the complexity of human needs is to highlight the universal human need for participation, influence, and dignity.[67] This need is basic to all persons, especially at a time when the stress on self-determination creates demands on every individual as regards their

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[64] Mental Capacity Act 2005, c. 9 § 5 (Eng. & Wales).

[65] Gill Livingstone et al., *Making Decisions for People with Dementia who Lack Capacity: Qualitative Study of Family Cares in UK*, 7771 British Med. J. 341 (2010); Liz Brosnan & Ellionoir Flynn, *Freedom to Negotiate: A Proposal Extricating 'Capacity' from 'Consent'*, 13 Int'l J.L. Context 58 (2017).

[66] Terry Carney, *Guardianship, 'Social' Citizenship and Theorizing Substitute Decision-Making Law*, *in* Beyond Elder Law: New Directions in Law and Ageing 1 (Israel Doron & Ann Soden eds., 2012); John Chesterman, *The Future of Adult Guardianship in Federal Australia*, 66 Austl. Soc. Work 26 (2012); J.L. Wright, *Guardianship for Your Own Good: Improving the Well-Being of Respondents and Principals in the USA*, 33 Int'l J.L. & Psychiatry 201 (2010).

[67] Mattsson & Katzin, *supra* note 7, at 113; Titti Mattsson, *National Ombudsman for the Elderly: A Solution for a More Responsive Welfare State?*, 36(3) Retfaerd 9 (2013).

participation and activity. Many older people need to be listened to as well as assisted at various points. Both individual and collective action is necessary if the healthcare and welfare systems of the nation are to be maintained for all who need them. Social workers have a central role to play in this regard, as do family caregivers who help incapacitated relatives.

CONCLUSION

In this Article, we have focused on some problems that arise in connection with social services for older persons whose capacity to make decisions has grown weak. The aim of our interdisciplinary research is to contribute to an improvement in the position of persons suffering from dementia. This is a very common situation in Sweden, but there is still a gap in the legislative framework that is needed to secure the interests of persons suffering from dementia. There is also a need for further research on these questions to guide the legislative body. The general approach is to analyze society's obligation to provide the resources and institutions required to overcome our shortcomings and vulnerabilities over the course of our lifespans.[68] Social institutions arise in response to these periodic vulnerabilities, and their purpose is to provide us with resilience.[69] Resilience consists in the resources we have built up throughout our lives by participating in society and being part of its institutions. The resources thereby accumulated furnish us with security and a capacity for agency. They are the tools we have for managing our embodied and embedded dependencies. The social-welfare services are a primary institution for persons with dementia. These services should thus be seen as a resource for enhancing our resilience and addressing our vulnerability.

However, neither legislation nor practice can be guided by paternalism. The focus should instead be on participation, influence, and respect for diversity and individual differences. This requires case-by-case solutions for each individual, not solutions based on group membership. Discussing the concept of 'participation' with vulnerability theory in mind fits very well with such a case-by-case approach that we argue is needed. One central concern is that the subject of 'participation' needs to be taken into account: who participates, and which considerations must be kept in mind for this person. Another concern is the way in which the society can provide options for

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[68] Mattsson & Katzin, *supra* note 7.

[69] Fineman, *supra* note 19.

'participation' through *representation*. The challenge here is how to ensure that all persons are guaranteed adequate social-welfare services.[70]

Our conclusion is that the risk of neglect and even danger for people with dementia in Sweden is too high today, and that this has legal causes which need be remedied. The uncertainties created by current legislation — for elder-care professionals, for relatives of people with dementia, and first and foremost for persons suffering from dementia — call for further legislative and policymaking efforts. Due to the social workers' inability to help those persons with dementia that refuse help but are in urgent need of some sort of assistance, the family has to interfere without clear legal support. In addition to the problems already discussed with such a scenario, providing care within the family inescapably leads, according to Fineman,[71] to a gender-biased distribution of the tasks involved (a pattern that still obtains in Sweden too).[72] This discussion does not, however, have room to be further developed within the Article.

In this Article we have emphasized the need, which is highlighted by vulnerability theory, for legal and policy alternatives that furnish cognitively impaired persons with greater assistance in decision-making. We have also stressed the need for studies in this field that take a multidisciplinary approach. With the very limited support it provides for decision-making by cognitively impaired persons, the Swedish system is in urgent need of discussion and revision.

ACKNOWLEDGEMENTS

The writers acknowledge funding from Forte Dnr-nr: 2015-01132; The Kamprad Family Foundation for Entrepreneurship, Research & Charity Dnr-nr: 2013-121; The Kamprad Family Foundation for Entrepreneurship, Research & Charity Dnr-nr: 2018-0020.

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[70] Titti Mattsson, *'Participation' for all? Challenges and Tools to Realize Participation for Vulnerable Persons with a Focus on Health Services*, *in* HUMAN RIGHTS IN ESSENTIAL PUBLIC SERVICES PROVISION 205, 207 (Marlies Hesselman, Antenor Hallo de Wolf & Brigit Toebes eds., 2017).

[71] *See id.*

[72] STATENS OFFENTLIGA UTREDNINGAR [GOV'T OFFICIAL INVESTIGATIONS], SOU 2014:28, LÖNSAMT ARBETE: FAMILJEANSVARETS FÖRDELNING OCH KONSEKVENSER [PROFITABLE WORK: THE FAMILY RESPONSIBILITY DISTRIBUTION AND CONSEQUENCES] (Swed.).